

Remarks of
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Subcommittee on Health and the Environment
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I am pleased to be here this afternoon. This session deals with what I believe will be the legal legacy of this decade. The Sixties will be remembered for the War and Protest. The Seventies for Energy and the Environment. The Eighties for the Epidemic.

And the Reagan Administration--for all its sweeping change and sudden shifts in politics--will not be remembered for its Space Shield, its secret wars, or its tax plans. The Reagan Administration will be remembered for its failure to deal with AIDS:

* We will remember and regret saving a few million dollars and losing hundreds of thousands of lives.

* We will remember and regret shying away from education and instead moving to mandatory testing.

* We will remember the President as showing less foresight with more information than any leader since Herbert Hoover or Neville Chamberlain.

Tragic ironies of the epidemic

It has been said that the Greek gods could not have created a drama that would be more tragic and more ironic than this disease at this time during this Administration.

* We have a Nation under the reign of a budget-slashing Administration and under siege by a budget-busting epidemic.

* We have an Administration that finds it difficult to tell heterosexuals about contraception that now must tell homosexuals about safe sex.

* We have a press corps that just five years ago could not use the words "gay" or "lover" and that now must explain how "bodily fluids" are exchanged.

- * We have a legal system that does not recognize sexual privacy among adults that now must deal with lovers' powers of attorney.
- * And gay people--who wanted only for the government to leave them alone--now have a real need for protection and assistance from governments that they fear more than ever, and with more reason.

It is tragic. It is ironic. And--in many ways--the epidemic has only begun. A vaccine and successful treatment are perhaps a long way away.

Social dislocation to come

In the meanwhile, it will fall to lawyers and politicians to work with medical and public health officials to ensure that the society that lives through the epidemic is a society in which we want to live.

The U.S. Public Health Service--in numbers that it concedes may be as much as twenty percent underestimated--has said that one to two million Americans are already infected with the virus believed to cause AIDS. They go on to say that more than a quarter million Americans will come down with full AIDS within the next five years.

If the epidemic continues at this rate, by the end of the Reagan Presidency, more Americans will have died of AIDS than died in Viet Nam.

I am not reciting these numbers or making this war-time comparison because I think that you need to be made more aware of the epidemic or its consequences. Most of you in this room understand that this disease is not just another chronic social problem and that it cannot be delegated or addressed with re-cycled ideas and thin budgets.

But I believe these numbers and the Viet Nam comparison are useful in understanding the political problems to come. We face social dislocation unlike any event other than war.

The losses of the Viet Nam war deeply changed this country and the world. International politics were re-aligned. Domestic policy was re-examined. Patriotism, party loyalty, and civil protest were all radically re-defined.

I hope to be proven wrong, but I believe that, in the next few years, AIDS will deeply change America as well. If AIDS claims as many lives as projected and costs the country the billions it appears it will, we can expect serious national stress and division. There will be fundamental changes in those institutions that middle-class Americans have come to take for granted: medical care, insurance, education, employment, and--most of all--privacy.

Groups like this one--in cooperation with our colleagues in medicine and public health--are our best hope for preventing these issues from dividing the country and from disabling our response.

AIDS not the worst case

In important ways, we are assisted in this work by the nature of the epidemic itself. As hard as it is to imagine, AIDS is not as bad as it might have been. It is infectious, but it is not easily caught. This is not the bubonic plague of the Middle Ages. It is not the flu of seventy years ago. AIDS is not the worst case scenario for medicine or public health or good law.

Public Education

Our first agenda must be to convey that fact to the public. At a time when public fear of AIDS is growing as fast as the epidemic, everyone who understands the basic facts of the disease is obliged to provide public education. We must face the ongoing dilemma of how to lower irrational fears while increasing the legitimate sense of urgency for research and for changes in sexual and drug practices.

Anti-gay ideologues

In providing this education, it is clear, however, that because of the politics of sexuality in this country, AIDS may be the worst case scenario not for medicine but for politics. We must deal with those ideologues and evangelists who have always hated gay men and lesbians and who are arming themselves with the new rhetorical weapon of AIDS. These people are AIDS terrorists, who will manipulate public fears, regardless of public health.

Groups like this one must be prepared to rebut these medical McCarthyites. You--with the credibility that you carry--will be able to reveal them for the propagandists that they are and to respond with facts.

Hard legal fights remain

But even after these educational and plainly political issues are dealt with, there will be many hard problems, many of them legal.

* We will have to evaluate what employment rights are in this country of opportunity.

* We will have to examine the costs of health care in our high-tech society.

* We will have to re-consider what we mean by insurance and risk-pooling in a time of uncertainty.

I don't pretend to have the answers to these issues, but I do have some thoughts about them that I want to discuss briefly.

Public Health is not versus Civil Rights

The first point that must be made loudly and clearly, especially in a legal conference, is that lawyers and politicians should--and do--support defending the public health. The responsible protection of individual rights is not at odds with the protection of public health. This is not--as the media often portray it--a question of individual rights versus public well-being. No one advocates such an extreme defense of individuals. To do so would be to defend yelling "Fire" in a crowded theatre.

During the AIDS epidemic, public health has not conflicted with civil liberties or civil rights. Quarantine is useless medicine and legal tyranny. Keeping a job is not inconsistent with good public health.

What we know and understand about this disease, we understand because AIDS patients and gay men have cooperated with scientists. When civil liberties for these people are threatened, the only outcome will be that the disease will be driven underground. We will know less and our chances of stopping the epidemic will grow smaller.

Employment Discrimination

Unfortunately, the Department of Justice has chosen to ignore the science and the law and to lend support to discrimination. In a recent opinion on protections for the handicapped, the Justice Department has said that people with AIDS can be fired or refused public services if the employer or service provider is afraid of the disease, whether their fear is rational or not.

In writing this tortured opinion, the Justice Department has ignored the law, which is clearly intended to change the fears and stereotypes that people hold about the disabled.

In endorsing this policy, the Reagan Administration has once more failed to listen to its health experts, who clearly understand that giving unfounded fears legal status encourages misunderstanding and panic.

A clear and coherent policy stance was available to the White House and its lawyers. Once again, they have chosen only to make the epidemic more complicated. Other than the simple politics of punishing the groups that now get AIDS most often, I cannot think of a reason why.

We must work to change this stance and to enforce the law as it was intended. Discrimination is bad private practice and bad public policy. And in this case it is bad for the health of the Nation.

It was not so long ago that people were afraid to work in an office with someone who had cancer? Who knows the lost productivity from such senseless fears? Who knows the human costs of people who dealt with a physical ailment only to be disabled by a social one?

More dramatically, during World War II, American soldiers lost their lives when military doctors refused to transfuse blood from black soldiers to white ones.

We cannot now allow employers to cater to prejudice that is contradicted by all public health. Discrimination against antibody-positive people will create a huge group of unemployables, a caste of people without the ability to provide for themselves.

We cannot afford such actions--economically or ethically. It is agreed that a person with antibodies presents no danger to fellow workers. If he or she can perform his or her work, they should have a right to keep working.

Health Care

And if they become too sick to work, they should have a right to be cared for. Those of you who know me, know that I have spent a long time working on problems of health care costs and access. AIDS brings these problems into bold relief.

Health Insurance

The American health care system is already strained by pressures ranging from the growing number of uninsured people to the declining adequacy of Federal programs. Many public hospitals--who are left with the responsibility of caring for all those without insurance--may be unable to bear the responsibility of caring for the increasing number of AIDS cases. Medicaid benefits, already impossibly low in many States, are threatened with cuts and are not available to all.

Adding to these pressures is the growing trend of antibody testing for individual insurance. (To my knowledge, no insurer is using antibody testing to underwrite groups.)

The problem is simply this: Costs must be paid. They will be paid by patients and their families, by insurance, by local taxes for hospitals, or by Federal taxes for health programs.

The American system of health insurance is designed to let people pool their risks of illness if they can afford to enter the pool. Some pre-existing condition restrictions have always limited entry, but--by and large--most healthy people are allowed in.

With the HTLV-3 antibody test--still not verified or approved for any use except blood transfusions--insurance companies have begun another restriction, restrictions based not on existing conditions but on potential ones.

We should examine this type of insurance prediction very carefully.

Today we have the science to screen for HTLV-3 antibodies. Soon we will be able to screen for other viruses and for genetic predispositions to heart attack or cancer. We are told that it will not be long before doctors can predict the medical histories almost literally from cradle to grave.

With such abilities available, insurance may become a new industry--pooling healthy people with healthy people and letting the devil take the hindmost.

No one expects insurance in America to be run on a charitable basis. But insurance companies enjoy a number of special treatments under regulation and law. They should be held responsible--at the State and Federal level--for their real debts and for their risk-pooling responsibilities.

Cost of Care

Making the issues of insurance more volatile are the questions of the costs of AIDS care. Statistics vary wildly from one study to the next. One says "diagnosis-to-death" care costs \$20,000, another says seven times that. Hospitals, insurers, and patients are understandably nervous about the discrepancies.

One partial solution has emerged clearly. We must be prepared--with AIDS and with other terminal illnesses--to provide hospice and home care and other alternatives to hospitalization.

I don't mean to suggest that we cut corners. If patients want to struggle to the last breath with every resource available, American medicine has tried to give them that choice. But if a patient wants only to be free of pain and to die with loved ones, we should not force them into institutions.

I have supported both Federal and private demonstration projects for alternative care for AIDS patients. Legislation to allow States to waive Medicaid requirements to provide such community care is a part of the House Budget bill now moving through Congress. I know that many insurers and employers have begun similar programs, and I would hope that there will be more.

Conclusion

Let me conclude by asking for your help with resources.

Many of you represent financial and corporate clients who must make private decisions on these issues and who can influence public policy.

If the epidemic continues, life and health insurance companies stand to lose billions of dollars. Hospitals stand to lose hundreds of millions more in care for those without insurance. And the Nation will lose productive citizens and billions in lost productivity.

As purchasers of health care, as taxpayers, and as fellow citizens, we will all share in these losses.

At the time of the initial outbreak of the disease it is easy to understand why it might have been regarded as a small issue. But much of the American financial and corporate community have failed to recognize the significance of the epidemic even now.

Powerful health lobbies have stood by, perhaps afraid of the controversy, as research budgets and education campaigns have gone wanting. Influential insurance lobbies have left the work of protecting their financial reserves to the National Gay Task Force and other diligent but small groups.

We all have a direct financial interest in making certain that the public and private sector respond fully to the epidemic--with research, with drug development, and with education. No market benefits from disease or panic.

But the Reagan Administration--penny-wise and pound-foolish and afraid to be seen helping gay men and drug abusers--has consistently short-changed all efforts. We will pay for that neglect.

Finally, let me enlist your help as people of reason and law. Simply by your presence here, I assume that many of you are aware of the legal problems posed by the epidemic. I urge you to work--as litigators, educators, or politicians--to bring compassion and urgency to our response to the epidemic.

One friend has said to me that this epidemic will bring us National Health Insurance or it will bring us camps.

I know gay men who make it a point to keep their passports in order at all times so they can leave the country if they have to. That people in this country should feel such anxiety is a sad commentary.

The epidemic has brought tragedy and loss to our country already. We cannot let it bring fear and repression as well.

Thank you.